PARENT REPORTED CONCERNS FOR TODDLERS WITH AUTISM SPECTRUM DISORDER SYMPTOMS

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STATEMENT OF THESIS APPROVAL

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ABSTRACT

The current study sought information from parents of children with Autism Spectrum Disorders (ASD) about concerns that they might have had prior to their child being screened for ASD. The aim was to determine which symptoms were most likely to be missed by parents, and which concerns are more likely to predict the results obtained from early childhood screenings. Factors contributing to the accuracy of parental report and their seeking assistance to address concerns were also investigated. Participants were drawn from the population of 813 children who were screened for ASD as part of the larger Each Child Study, a project intended to investigate the feasibility of systematically screening children for ASD during visits to pediatricians or primary care physicians. As part of this study, children were initially screened at the pediatrician's office and those who screened positive for ASD were called for a follow-up telephone interview. The sample for the current study included the 162 parents who were successfully contacted for this follow-up interview. Ages of participants ranged from 15 to 31 months, with a mean age of 22 months. Fifty-eight percent of participants were male while 35 % were female. During the phone interview, participants were first asked to report any concerns about their child's development and then to confirm the responses given on the screeners completed at the pediatrician's office. Those who continued to screen positive after the

phone interview were invited for an in-person screening to confirm results. Results of this study suggested that parents of children who screened positive for ASD missed social behavior and stereotyped behavior symptoms more frequently than other ASD symptoms. Parents accurately reported language delay more frequently than other ASD symptoms. No specific parental concern was found to be predictive of screening outcome but findings suggest that the presence of concerns in more than one category may predict a positive screen for ASD. Parents who reported concerns about abnormal social behavior and stereotyped repetitive behaviors were more likely to have sought assistance for their concerns than parents who had reported concern in other areas. Maternal age and the presence of older siblings do not appear to impact a parent's ability to recognize and become concerned by ASD symptoms and the influence of family structure (number of parents in the home) could not be assessed because of the limited range of the sample on this factor. Overall, results suggest that parents could benefit from additional information about the early signs of autism, specifically normal versus abnormal social interaction and repetitive, stereotyped behavior.

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INTRODUCTION

Early Identification of Autism Spectrum Disorders

Children with Autism Spectrum Disorders (ASD) appear to benefit most in terms of long-term outcomes when intensive interventions are started early in life (Bailey et al., 2005). According to researchers, children who begin receiving appropriate interventions between 2 and 4 years of age make considerably greater progress than children who begin receiving the same intervention at a later age (Anderson, Avery, DiPietro, Edwards, & Christian, 1987 as cited in Rogers, 1996; Fenske, Zalenski, Kran, & McClannahan, 1985; Lovaas,1987; McEachin, Smith, & Lovaas, 1993; Rogers & DiLalla, 1991; Rogers & Lewis, 1989). Moreover, for children with ASD, there seems to be a critical period for intervention that is accounted for by the unique plasticity afforded to young children who are in early developmental stages (Rogers, 1996).

Findings supporting the benefits of early intervention are plentiful. There is evidence that preschool-aged children with ASD who have 2 years or more of appropriate intensive intervention can show significant increases in scores on intellectual and academic performance tests (Dawson & Osterling, 1997; Filipek et al., 1999; Harris & Handleman, 2000). Further, children who receive intervention early, that is, before the age of 4 years, are more likely to develop speech than those who receive the same intervention after the same age (Goin & Myers, 2004).

Symptoms of ASD have been shown to emerge in the first year of life (Baranek, 1999; Dawson, Osterling, Meltof, & Kuhl, 2000; Maestro, Casella, Milone, Muratori, & Palacio-Espasa, 1999; Osterling & Dawson 1994; Ozonoff, 2007). Ozonoff has examined siblings of children with autism trying to determine how early symptoms actually manifest themselves in order to make as early and as accurate a diagnosis as possible. To this end, the participants in her study were assessed at 6, 12, 18, 24, and 36 months of age to determine the existent of ASD symptomatology. Results of the study showed that, for children who ended up being diagnosed later in life, symptoms emerged gradually between the ages of 6 and 18 months. The majority, however, displayed symptoms by 18 months of age, and very few displayed ASD symptoms prior to 12 months.

The findings from Ozonoff's research are similar to those found during the field trials for the diagnostic criteria for pervasive developmental disorders, in particular, autistic spectrum disorders, found in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV) of the American Psychiatric Association (APA, 2000). According to DSM-IV researchers who collected data on 454 children with a diagnosis of Autism Disorder, the average age when symptoms were reported to begin was just over a year.

Prior to 1 year of age, symptoms of an Autism Disorder include hypersensitivity to noise and tactile input, sleep and feeding difficulties, stereotyped movements, and poor eye contact (Dawson et al., 2000). In addition, children with autism have been shown to develop more slowly than typically developing peers, and many show a failure to develop critical prerequisite social behaviors such as imitation, pointing at objects, and

communicating using gestures (Dawson et al., 2000; Hoshino et al., 1982; Maestro et al., 1999).

A study examining infants 9 to 12 months of age found that deficits in sensory-motor function and social reciprocity could accurately predict 93.75% of cases of autism diagnosed later in life (Baranek, 1999). Other early developmental red flags include stereotyped vocal or verbal emissions and repetitive behaviors at 1 year of age (Maestro et al., 1999; Ozonoff, 2008); however, some researchers suggest that stereotyped, repetitive behaviors have a later onset compared to impairments in social interaction and communication (Adrien et al., 1993; Siegal, Pliner, Eschler, & Elliot, 1988; Stone, Lee, Ashford, & Brissie, 1999).

According to Osterling and Dawson (1994), video data from "first birthday party" home videos have shown that 1 year old children with autism can be differentiated from typically developing children by the frequency with which they look at other people. In a similar study using videotapes, Werner, Dawson, Osterling, and Dinno (2000) showed that children 8 to 10 months of age can be distinguished from same-age typically developing children by their failure to orient when their name is called. The failure to orient to name has also been found to distinguish somewhat older children, including those who are 1-year or older, suggesting that this symptom may be one of the early emerging symptoms in toddlers, and may also be one of the most stable indicators in this age group. Mars, Mauk, and Dowrick (1998) also analyzed videotape data of children between the ages of 12 and 30 months in order to evaluate the frequency of certain behaviors that might predict whether the child will be later diagnosed as having either a Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or

Autism Disorder. The researchers found that nine behaviors accurately predicted all children diagnosed with an Autism Disorder, and identified correctly 96% of the typically developing children who were studied. The behaviors that distinguished the two groups of children were following verbal directions, speaking words, looking at faces and people, imitating vocalizations, failing to orient to name, pointing vaguely, exhibiting alternating gaze, and showing objects. However, of all these predictor variables, decreased visual gaze at facial features and the failure to show objects to other people were the strongest predictors of an Autism Disorder.

Using recent retrospective parental reports, Wimpory, Hobson, Williams, and Nash (2000) investigated the aspects of social engagement that distinguish children with autism from typically developing children. A semistructured interview was given to 10 parents of children with autism, and 10 parents of typically developing children before a formal diagnosis was made. The interview focused on behaviors present during the first 24 months of life. Results showed that infants with autism exhibit a range of abnormalities that indicate significant limitations in social engagement, including person-to-person nonverbal communication, interpersonal contact, and triadic person-person-object interactions. These abnormalities, though capable of predicting ASD, were not significant problems for the children in the control group.

Ozonoff (2007) investigated object use at 12 months of age to better understand the relationship between atypical object use at 12 months and the child's diagnostic status 2 years later, or 36 months of age. The researchers showed that infants later diagnosed with ASD displayed significantly more atypical object use at 12 months of age. Atypical object use was defined as rotating, rolling, spinning, and unusual visual exploration of

objects that were presented for 30 seconds. The study showed that unusual visual exploration of objects was observed at particularly high rates among children who later received a diagnosis of an ASD, which led these researchers to suggest that this behavior may be a distinctive feature of early autism, or in children around 1 year old.

Distinguishing ASD from Other Developmental Conditions

Autism can often be differentiated from other developmental delays in young children by examining a child's skills, or impairments, in communication, social interaction, play, and imitation (Dahlgren & Gillberg, 1989; Stone, Hoffman, Lewis, & Ousley, 1994). In fact, researchers have shown that repetitive behaviors may help distinguish young children with Autism from other young children who have other types of developmental delay. Higher-level repetitive behaviors, including verbal rituals, unusual preoccupations, and unusual sensory interests, have been found to be significantly correlated with children receiving a diagnosis of autism when other factors are held constant. This includes severity of developmental delay, chronological age, and levels of adaptive behavior. However, lower-level repetitive behaviors, that is, complex mannerisms, repetitive use of object, and self injury, do not appear to be significantly correlated with a diagnosis when these same factors were taken into account (Mooney, Gray, & Tonge, 2006). However, some research suggests that in children younger than 2 years of age, it may be difficult to differentiate ASD from other disabilities such as learning disabilities and speech delay. Cox et al. (1999) found that, at 20 months of age, both children with ASD as well as those with diagnosed learning disabilities (LD) only, displayed abnormalities in some of the same areas: seeking to share enjoyment with

others, nodding, and imaginative play. However, by 42 months, the children with ASD were significantly less likely to point to show interest, use conventional gestures, seek to share enjoyment with others, engage in imaginative play, or nod their heads than those with LD only. Similarly, researchers found that, when assessed using the ADI-R, a significant portion of typically developing children as well as those with speech delay displayed abnormalities in behaviors such as offering comfort, offering to share, and nodding at 20 months but that these abnormalities were not found when the ADI-R was readministered at 42 months.

When comparing the presentation of mental retardation to the presentation of ASD in young children, it appears that children with ASD orient to their names and look at others less frequently than children with mental retardation in the absence of ASD (Dawson et al., 1998 as cited in Werner, Dawson, Osterling, & Dinno, 2000; Osterling, Dawson, & Munson, 2002). However, increased repetitive behaviors were observed in both an ASD group as well as an MR-only group, distinguishing both groups from typically developing 1-year olds but not from each other (Osterling et al., 2002).

Parents' Role in Early Identification of ASD Symptoms

For several reasons, parents are in the optimal position to recognize abnormalities in young children. They are generally provided the opportunity to observe their children over time and in numerous settings, allowing them a uniquely thorough perspective on their child's development. In fact, some research suggests that parents may be as sensitive to abnormalities in their children as a screening instrument. Glascoe, Macias, Wegner, and Robertshaw (2007) found that, when obtained systematically, parental

concerns can be used in place of standardized screening measures to make accurate referral decisions. Results of this study suggest that parents are most accurate in identifying abnormalities when reporting concerns in certain categories. Those who reported concerns about motor delay, language delay, global developmental delay, school problems, or cognitive problems accurately identified 79% children with disabilities. Likewise, the absence of concern or concern in other areas accurately identified 72% of typically developing children. Some parents, whose children were determined to be developing normally, inaccurately expressed concern. However, these parents tended to raise fewer concerns about their child than accurately concerned parents. In fact, parents with accurate concerns raised twice as many concerns about their child as those who were inaccurately concerned. Often, the parents of typically developing children expressed concern about language delay only. Of parents whose children were developing abnormally, those who were not concerned were more likely to have children with significantly higher performance in gross and fine motor skills than those who were concerned. In a similar study, Glascoe (2003) explored both to what extent parent's concerns can be depended on to detect mental health problems in general as well as which concerns are most associated with significant behavioral or emotional problems. He found that parents' concerns about behavior or social skills were strong predictors of mental health problems and correctly identified 76% of children who were determined to have such problems using screening measures. Moreover, 72% of typically developing children were identified by the absence of such concern. In children under 4 ½ years of age, concerns were slightly less sensitive in detecting abnormalities when compared to children over 4 ½ years of age. Parents of younger children were more likely to have

concerns even when their children did not display mental health problems. Data did not lead to conclusions about factors contributing to parents' failure to report concern for children who, after screening, appeared to have mental health problems.

In some cases, parents fail to recognize the signs and symptoms of ASD in their children or fail to respond to these symptoms with concern (Cox et al., 1999). There are several possible explanations for this. At times, parents appear to experience progressive detachment in affective interactions with their child. This detachment is characterized by the parent's increasing ability to tolerate the child's social and emotional withdrawal without recognizing it as a problem (Maestro et al., 1999).

Research has indicated that parents of children later diagnosed with ASD report certain developmental abnormalities earlier or more frequently than others. Studies exploring this area often make use of retrospective parental report or the analysis of home videos (e.g., videos of first birthday parties). Language delay has been found to be among the earliest and most frequent of parental concerns. One retroactive study of parental report of first concern was conducted by De Giacomo and Fombonne (1998). This study aimed to identify factors associated with the early detection of pervasive developmental disorders. Children referred for evaluations were assessed using the Autism Diagnostic Interview (ADI), direct observation, and other standardized tests. Data regarding the first symptoms to arise parental concern were analyzed. Researchers found that more than half of parents whose child had an ASD recalled language delay as the first concern that they had about their child's development. Abnormal social-emotional response and other autism-type behaviors were rarely recalled particularly as the first parental concern. A study conducted by Young, Brewer, and Pattison (2003) produced similar findings

regarding language delay. For this study, a questionnaire was given to the parents of 81 children under age 10 who had been diagnosed with Autism. The first part of this questionnaire used an open-ended format to ask parents which behaviors first caused them to be concerned. Delayed language was the most commonly reported early concern. However, lack of interest in toys and odd social behaviors provoked parental concern at an earlier age. Excessive tantrums and crying were also frequently reported early concerns. Most of these concerns were reported to have been present before the child was 3 years of age.

Some studies obtained data about parental concern before a diagnosis was made. In their study aimed at determining early indicators of Autism Spectrum Disorders, Wetherby et al. (2004) used the Communication and Symbolic Behavior Scale Developmental Profile Infant- Toddler Checklist and a videotaped Behavior Sample (CSBS-DP- ITC and BS, Wetherby & Prizant, 2002) to screen 3026 children under 24 months of age. After three levels of screening, the sample was broken up into three groups of 18 children each. One group was identified as having ASD, one group had developmental delays but ASD was ruled out, and one group was typically developing. There is one question on the CSBS-DP that asks parents to describe any concerns about their child's development. Parent responses to this question were categorized into concerns about language, concerns about social development and behavior, concerns about cognitive and motor development, and family history of developmental disabilities. The analysis of parental concern showed that, when asked in the context of a checklist about communication milestones, a majority of parents in all three groups had concerns about their child's communication development. However, the authors found that a

larger percentage of parents whose children were later diagnosed with ASD had more concerns of any type than those whose children were in the other two groups. Additionally, most parents of children with ASD had concerns in more than one area of development. Many of them expressed concern about social development or behavior as well as communication development. This finding was replicated by other studies (Howlin & Moore, 1997; Siegel et al., 1988).

Several studies suggest that parents, on average, recognize the symptoms of ASD before their child reaches 2 years of age (Charwarska et al., 2007; De Giacomo & Fombone, 1998). De Giacomo and Fombone (1998) found that one third of parents had recognized abnormalities in development by their child's first birthday and 80% had recognized abnormalities by their second birthday. Meanwhile, other studies show that the average age of diagnosis for ASDs falls between 36 and 61 months (Landa, Holman, & Garret-Mayer, 2007; Rutter, 2006; Wetherby et al., 2004; Wiggins, Baio, & Rice, 2006). This indicates an apparent gap between age when parents first recognized symptoms and age of diagnosis. In fact, studies asking parents of autistic children to retrospectively identify initial concerns found that there is often a 4-8-month gap between the time parents first became concerned and when they sought professional advice (De Giacomo & Fombone, 1998; Maestro, Casella, Milone, Muratori, & Palacio-Espasa, 1999; Smith et al., 1994). Determining what is causing this delay between symptom onset, recognition, and diagnosis is imperative to helping children obtain needed treatment. This delay could be explained by parents doubting the significance of the particular abnormalities that they notice, therefore forgoing seeking professional advice. Alternately, because most previous research has relied on parental hindsight or home

video analysis, it may be that developmental abnormalities were present at a young age but that these abnormalities failed to initiate parental concern at that time.

Several factors may influence the onset of parental concern about their child's development. Parents are more likely to worry when child's behavior disrupts family routines and when the child demonstrates low social competence (Ellingson, Briggs-Gowan, Carter, & Horwitz, 2004). Delayed onset of social smiling may also be catalyst for inciting parental concern (Charwarska et al., 2007). Comorbid conditions seem to precipitate the recognition of ASD symptoms. The onset of parental concerns tends to be earlier when autism is accompanied by severe symptoms such as medical problems, mental retardation, delays in motor milestones, and significant language delays (De Giacomo & Fombone, 1998).

Family structure and parental characteristics may also influence the emergence of concerns. Maternal age may be a factor influencing that age at which symptoms of ASD are recognized. Some research suggests that older maternal age or use of infertility treatments may lead to later recognition of ASD. This may be because older parents are more tolerant of abnormalities (Charwarska et al., 2006). Although research to date has failed to show that birth order and number of siblings are related to the age at which parents recognize the symptoms of ASD (Charwarska et al., 2006, Maestro et al., 1999), more educated, and highly anxious, parents appear to be more apt to recognize abnormalities in their child (Horwitz, Gary, Briggs-Gowan, & Carter, 2003.)

Role of Pediatricians in Making Referrals

Worried parents often report their concerns to their pediatrician. It follows logically then that pediatricians may be in an ideal position to help with early identification of ASD. Although formal screening instruments in the hands of pediatricians may facilitate the screening process, a recent survey showed that only 8% of primary care pediatricians routinely screen for ASDs (Dosreis, Weiner, Johnson, & Newschaffer, as cited in Johnson, Myers, & Council on Children with Disabilities, 2007). Many practitioners attempt to identify potential developmental problems using a clinical assessment without the use of a screening instrument or checklist (AAP, 2003). This practice may result in fewer referrals for young children who present with ASD symptoms in isolation given the fact pediatricians are most likely to make an early referral only when biological risk factors such as very low birth weight or perinatal complications are present, or when communication and language delays coexist with significant physical, sensory, or cognitive disabilities (Prizant & Wetherby, 1993).

Results of a recent study demonstrated that screening rates for ASD can be increased through systematic screening using a standardized instrument. This study was conducted in conjunction with an initiative to increase the rate of systematic, standardized screening of toddlers for developmental delays and resulted in an overall screening rate of 75% across several pediatric practices (Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005). There are several obstacles to screening for ASD in a pediatric practice. These obstacles include lack of time, lack of staff to implement screening, and inadequate reimbursement for screening (AAP, 2003). Contemporary

research, however, aims to identify effective screening measures for use in this setting (see Gabrielsen, 2009).

The American Academy of Pediatrics (AAP) published guidelines for screening all children at ages 18 and 24 months using an autism-specific screening questionnaire. These guidelines included a technical report published in 2001, which has been updated and replaced by two clinical reports that detailed best practice in evaluation, identification, and management of ASDs. The most recent report, published in 2007, focused on evaluation and identification and includes an algorithm for identifying risk factors in children of all ages.

The algorithm is to be used during either preventative care visits or visits for autism-related concerns. It explains a practice of scoring screeners to determine the presence of risk factors. These risk factors include: (1) the presence of a sibling with ASD; (2) parental concern; (3) other caregiver concern; and/or (4) pediatrician concern. If the child has none of these risk factors, the recommendation is that the child be screened for ASD again at an older age (18 and 24 months). If the total of risk factors is one and the child is under 18 months old, he should be screened for social and communicative skills. If the total of risk factors is one and the child is over 18 months old, she should be screened with an autism-specific screener. If the results of this screening are negative, it is recommended that the practitioner provide parental education pamphlets published by the AAP and schedule an extra follow-up visit within 1 month (Gupta et al., 2007; Johnson et al., 2007). If autism-specific screens are administered and return positive results, or if the child's total of risk factors are equal to 2 or more, it is recommended that parental education be provided and referrals are made for

comprehensive ASD evaluation, early intervention/early childhood education services, and audiologic evaluation. A follow-up visit is also recommended.

Typical Procedures for Early Screening of ASD

There are several varied methods used when screening for ASD. As was mentioned above, formal screening instruments have advantages over clinical assessment and are recommended by the AAP in their guidelines for ASD screening (see sections above). Specific Screeners such as The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) are frequently used to screen for ASD in toddlers. It is a questionnaire consisting of 23 questions that can be answered "Yes" or "No" (see Appendix C). Six of these questions are considered to be critical items. It is designed to be used for children 18- 30 months of age.

General screeners also have some utility in identifying developmental abnormalities including ASD. The Communication and Symbolic Behavior Scales Developmental Profile-Infant Toddler Checklist (ITC; Wetherby & Prizant, 2002) was designed to be completed by the parent regarding their child's development.The ITC identifies developmental deficits in several domains, including social behavior, speech, and symbolic communication. The ITC is designed for children from 6 to 24 months of age.

A comprehensive evaluation including several components is important in diagnosing autism. This evaluation should include a thorough developmental and health history, a psychological assessment, a communicative assessment, and a medical evaluation. Diagnostic information should be gathered through both direct observation

and interviews with parents or teachers (Committee on Educational Interventions for Children with Autism, 2002). The Autism Diagnostic Observation Scale (ADOS) (Lord, Rutte, DiLavore, & Risi, 1994) is a standardized instrument that is frequently used to obtain diagnostic information from direct observation. The ADOS is often used in tandem with the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994), a parent interview designed to illicit relevant diagnostic information from parents or caregivers. A diagnosis is made using both of these instruments along with clinical judgment applied to the diagnostic criteria specified by The Diagnostic and Statistical Manual of Mental Disorders – fourth edition (American Psychiatric Association, 2000).

Rationale for the Current Study

Many studies have investigated the value, and thus accuracy, of reported parental concerns in early identification of ASD. While some researchers have demonstrated that parents of young children have concerns about abnormal early development of children who are later diagnosed with ASD, other investigators have shown that time elapses between the report of concerns and the age when symptoms are first recognized and the ASD diagnosis is made. One possible explanation is the methodology often used to study early symptoms, that is, retrospective home video analysis, and retrospective analysis of parental concern, that is, asking parents to report what concerns they first had about their child. Asking parents to report concerns they had months, if not years, earlier brings into question the validity and reliability of the data, but so does the use of home videos. While research using home videos to study the onset of ASD symptoms, and associated parental concerns, has contributed to the research base, the *source* of data presents methodological

challenges. This includes the inability of investigators to control the content, quality, and representativeness of the data (Palomo, Belinchon & Ozonoff, 2006). Parents, rather than researchers, control the content of the videos; therefore, questions are raised as to parental bias such as excluding data on the video that represents unwanted or negative behaviors.

The present study obtained information about parental concerns regarding their child's development shortly before the child was screened for ASD in hopes of learning more about how to identify ASD as early as possible. The study also investigated the specific concerns of parents of children thought to have ASD, including the concerns that caused parents to seek professional assistance. Further, the relationship between family structure and the presence (or absence) of concerns reflecting symptoms that were found to be present during in-person screening was analyzed to ascertain if factors such as maternal age, the number of parents in the household, older siblings living in the home, and presence of a sibling with an ASD contributed to a parent reporting symptoms of ASD accurately.

Research Questions

(1) Are there critical concerns reported on The Parent Concerns Questionnaire that predict whether a child is determined to have ASD or not?

(2) If the parent sought assistance to address concerns about his/her child's development, which concerns reported on the Parent Concerns Questionnaire caused them to seek assistance?

(3) Which Autism Spectrum Disorder symptoms found to be present in the child during

in-person screening using The Autism Diagnostic Observation Schedule- Toddler (ADOS-T) and The Mullen Scales of Early Learning (Mullen) Fine Motor and Gross Motor scales are most likely to have been reported by the parent on The Parent Concerns Questionnaire?

Supplemental Questions

(1) Does having one or two parents in the home predict whether parents accurately report symptoms of ASD?

(2) Does the presence of an older sibling predict whether parents accurately report symptoms of ASD?

(3) Does the presence of another child with ASD or any other disability predict whether parents accurately report symptoms of ASD?

(4) Does maternal age predict whether symptoms of autism are accurately reported?

METHODS

Procedures

Institutional Review Board

All aspects of the study were approved by the University of Utah Institutional Review Board on December 9, 2006 (IRB#00015927). Approval was amended and renewed on December 12, 2007 and November 21, 2008.

Training of Researchers

Three researchers were trained to administer the Parent Concerns Questionnaire (PCQ) (Ozonoff, 2008)(see Appendix A) in accordance with the instructions provided by the author. Training included an explanation of how to ask follow-up questions in order to code a parent response into the correct symptom category. Researchers were instructed not to ask follow-up questions when the parent response was easily coded into a category without doing so.

Collection of Parent Concerns

All parents contacted for a phone interview as part of the Each Child Study gave verbal permission to be asked some follow-up questions. During the phone call, before the administration of the follow-up questionnaires, parents who agreed to participate were

administered the PCQ. Then, if the participant had screened positive on The Modified Checklist for Autism in Toddlers (M-CHAT) that they completed at the pediatrician's office, the follow-up interview form of the M-CHAT was administered. For this interview, only failed responses or those responses that the examiner was concerned may not have been answered accurately were administered. Follow-up interview items were scored in the same manner as the M-CHAT; a positive screen for ASD risk coincides with a score of three or more failed responses or two or more failed critical responses. Similarly, a follow-up administration of the Communication and Symbolic Behavior Scales Developmental Profile-Infant Toddler Checklist (ITC) was conducted if the participant screened positive on this instrument at the pediatric practice. This administration simply involved repeating items for which the parent had indicated behavior consistent with developmental delay on the initial administration (failed responses). For the purposes of this study, a positive screen on the phone administration of the ITC coincided with a score below a cutoff score for the child's age.

If a parent completed and signed the release form in the pediatric practice but failed to complete one or both screening questionnaires, the PCQ was administered followed by any missing or incomplete M-CHAT and ITC questionnaires. Phone interviews were conducted in Spanish when parents indicated that Spanish was spoken in the home.

In-person Screening

In-person screening occurred only with those who screened positive at initial screening in a category other than or in addition to speech-language delay (see Figure 1).

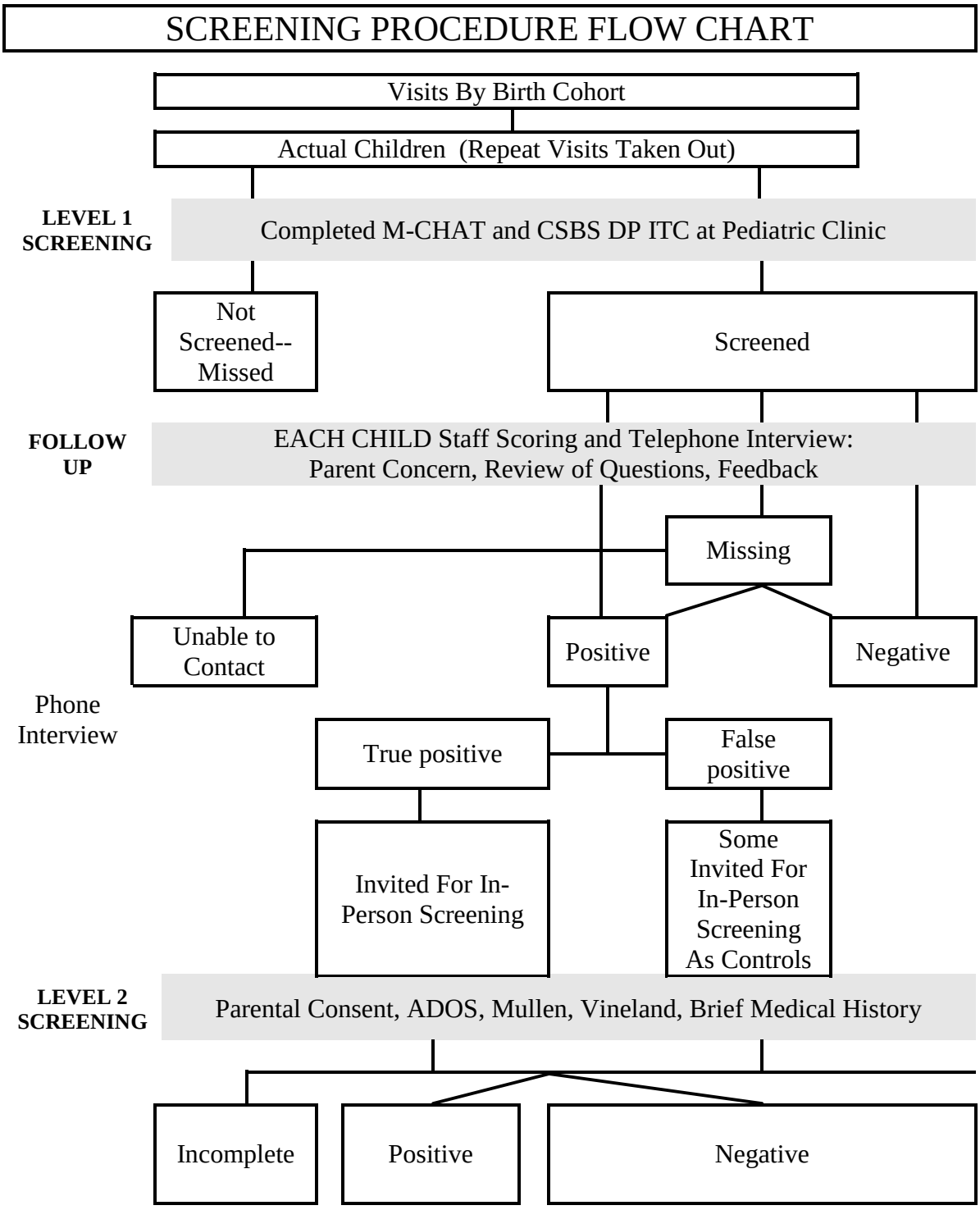

Figure 1. Each child study flow diagram

Those who screened positive for speech delay only were sent a letter explaining the results and providing a list of referrals but were not invited for in-person screening. Participants who qualified for in-person screening were invited to come into the Utah Autism Research Project for an in-person screening conducted under the supervision of an expert licensed psychologist. Additionally, four graduate research assistants, all trained and qualified to administer these instruments, participated in the administration of in-person screenings. This screening consisted of clinical judgment based on the administration of the ADOS-T (Lord et al., 2006), the Mullen, the ITSEA, the Vineland-II, and a brief medical history form (see Appendix E).

All administrations of the ADOS-T were conducted by trained research assistants under the supervision of the licensed psychologist and expert, and one graduate research assistant. The examiners received training on the unpublished ADOS-T from the authors of the test, and permission was given by the publisher for the use of the prepublication version of the ADOS-T for this particular research project.

Clinical judgment was used to determine the presence or absence of symptoms within the specific domains into which parent concerns had been coded using the PCQ. Clinical decisions about the presence of ASD were made by a licensed psychologist with expertise in autism diagnosis. The psychologist oversaw all in-person screenings, with judgments supported by the administration of several standardized instruments. This included the ADOS-T, the Mullen, The ITSEA, and the Vineland. A clinical judgment form (see Appendix D) was used to make notes during the administration of screening instruments. Then, to ensure the reliability of the judgments recorded on this form, the team of evaluators met and watched all videotaped administrations after data collection

was completed. At this time, they reached a consensus on the presence or absence of symptoms in each category and marked the form accordingly. The expert licensed psychologist and all evaluators, with the exception of one research assistant who scheduled appointments, were blind to previous screening results.

All screening instruments were scored by trained researchers. Initial feedback was given to parents during this visit and a report of in-person screening results was sent to the address provided. Referrals were also provided based on results. All in-person screens were videotaped. Whenever necessary, instruments and interviews were administered in Spanish. All data from scored screening instruments along with brief medical history and demographic information obtained from the pediatric practice was entered into a database. Data was then double entered by another research assistant to ensure accuracy.

Participants

The Each Child Study

Participants for the current study were drawn from a larger study of children screened for ASD in the Each Child Study. The Each Child Study is a research project intended to investigate the feasibility of systematically screening children for ASD during visits to pediatricians or primary care physicians (PCP) using guidelines established by the American Academy of Pediatrics. As a part of the Each Child Study project, parents of all children born in 2006 who were seen in the practice between February 25, 2008 and August 31, 2009 were asked to complete research questionnaire measures intended to identify children with symptoms of ASD. Parents who consented to participate in the

study were instructed to complete the questionnaires in the waiting room of the pediatric clinic. These questionnaires included both The Modified Checklist for Autism in Toddlers (M-CHAT: Robins et al., 2001) (see Appendix C) and The Communication and Symbolic Behavior Scales Developmental Profile- Infant Toddler Checklist (ITC: Wetherby & Prizant, 2002).

All positive screens on the questionnaires completed during the visit were confirmed during a follow-up phone call by the researchers. At the time of this call, a questionnaire designed to solicit information about any initial parental concerns was administered. Children who had positive screens for ASD after the follow-up phone assessment were then evaluated during an in-person evaluation at the Utah Autism Research Project, located at the University of Utah.

A total of 1,008 children, all born in 2006, were eligible for screening during the study period, February 25, 2008 through August 31, 2009. Of the 1,008 eligible children, 81%, or 813 eligible participants were screened. Ninety-five children, or 19%, of the eligible children were not screened. The reasons varied but 12% of the potential participants' parents did not participate because personnel at the clinic inadvertently failed to offer them questionnaires.

Efforts to determine the reason(s) that parents declined to participate in the screening are included in Table 1. However, it should be noted that when "language difficulties" were the reported reasons, this was determined by interview rather than parent report.

Table 1

Reasons for Declining Screening (Data from Gabrielson, 2009)

	Already Receiving Services	Doctor Said Child Does Not Have ASD	Parent Did Not Think Child has ASD	Child Had Changed	Language Barrier[c]	Too Busy	No Concerns	No Reason Given	Cancelled/ No Show[b]
Level 1[a] *n* = 72 (7% of eligible)								72[a]	
At phone interview *n*=5		2			(1)			3	
Level 2 *n* = 22[b]	2	2	1	1	(2)[c]	5	2 (4)[d]	3	8

Note. Figures enclosed in parentheses represent parents who stated a different reason for declining participation.

[a] Parents typically declined repeat screenings. These figures represent decline of screening, not repeat screening. Parents were not questioned by clinic staff regarding declined participation.

[b] Five parents who were invited to bring children in as control subjects were no-shows or cancelled. They are not included here.

[c] Language barrier subjective judgment based on difficulties in communication during phone interview. Both parents listed here are also represented in "Too Busy" column.

[d] Parent expressed no concern during phone interview (2 also represented in "No-shows", 1 in "Too Busy," 1 in "No Reason"

According to data from the 2000 Census report (U.S. Bureau of Census, 2000), there are approximately 276,984 individuals residing in the area served by the pediatric practice where study participants were drawn. The ethnic makeup of this area's population was 45% Caucasian, 17% Hispanic or Latino, 3% Asian, 3% Pacific Islander, 2% African American, 1% Native American, and 10% "other" or multiracial. Thirty-eight percent of the parents did not indicate his/her ethnicity or race, possibly a result of the fact that race/ethnicity was an optional category on the questionnaire. For the most part, the sample was considered representative of the geographic location of the families, that is, greater Salt Lake City, Utah. However, the percentage of children identified as non-Hispanic Caucasians, and the percentage of children identified as "other" in the sample appears to under-represent the demographic area of the participants. It should be noted that of all individuals screened as part of The Each Child study, 66 were from Spanish-speaking families, and these participants received the questionnaires (M-CHAT, ITC, PCQ) and in-person assessments (ADOS-T, Mullen, Vineland-II) in Spanish.

Demographic Characteristics of Current Study Sample and N

The sample for this study included 162 parents, that is, those who were successfully contacted by phone for a follow-up interview. There were 223 parents who met the criteria for a phone interview as a result of: 1) their screening positively on one or both of the initial screening questionnaires, The Modified Checklist for Autism in Toddlers (M-CHAT), or The Communication and Symbolic Behavior Scales Developmental Profile- Infant Toddler Checklist (ITC);or 2) the parent indicated concern

about their children in a “blank space” provided at the bottom of the M-CHAT questionnaire.

Demographic information regarding all participants is displayed in Table 2. Table 2 also includes data for children who screened positively on the initial questionnaires but could not be contacted for a phone interview as well as those who screened positive after the phone interview but either declined to participate in the in-person screening or failed to show up. The ages of participants ranged from 15 to 31 months, with a mean age of 22 months. Fifty-eight percent of participants were male and 35% were female. Parents of all Each Child participants were prompted to indicate the race or ethnicity of their child at the bottom of one of the parent report questionnaires. However, a response to this enquiry was designated as optional. Therefore, 38% of all Each Child parents and 35% of the parents included in the current study did not indicate the race or ethnicity of their child. The age and racial/ethnic makeup of the current study’s sample (those contacted via phone) was as follows: 36% Caucasian, 18% Hispanic, 2% African American, 3% Asian, 0.6% Native American, 6% Pacific Islander, and 0.6% Other, 7% indicated multiple race/ethnicity. Table 2 compares the demographic characteristics of the current sample to those of the entire Each Child Study sample.

Three parents who received a phone interview, but whose children had been previously diagnosed with autism, were excluded from the study. The investigators were unable to contact 58 of the parents whose children had been screened positive for ASD on the initial screeners. As a result, no data were collected regarding parental concerns for these individuals.

Table 2

Demographic Characteristics of Sample as Compared to Other Groups

Characteristics	Participants for entire Each Child Study (*n* = 813)	Participants For the Current Study (*n* = 162)	Screened Positive but Could Not be Contacted by Phone (*n*=58)	Did not Show for or Declined In-Person Screening (*n* = 27)
Age, mean, (*SD*) mo.	21.8 (4)	21.7 (5)	21.3 (4)	22.8 (4)
Gender, No. (%)				
Male	395 (49)	94 (58)	28 (48)	18 (69)
Female	375 (46)	56(35)	23 (40)	9 (33)
Not Indicated	43 (5)	12 (7)	5(9)	--
Race/Ethnicity, No. (%) (total exceeds				
Caucasian, not Hispanic	357 (44)	58 (36)	16 (28)	9 (33)
Hispanic	140 (17)	29(18)	13 (22)	4 (22)
African-American	18 (2)	3(2)	2 (3)	--
Asian	28 (3)	5 (3)	2 (3)	--
Native American	11 (1)	1 (0.6)	2 (3)	1 (6)
Pacific Islander	24 (3)	9 (6)	4(7)	--
Other	6 (1)	1 (0.6)	--	--
Indicated multiple race/ethnicity	71 (9)	11(6.7)	7(12)	--
Did not indicate	312 (38)	56 (35)	26 (45)	14 (54)
Spanish Speaking Questionnaires, No. (%)	66 (8)	12 (7)	7 (12)	45 (8)

Analyses using a chi-square test failed to show significant differences in the racial and ethnic makeup of the group who were successfully contacted by phone and, therefore, included in the current study's sample and those who were screened at the pediatric practice as part of the Each Child study but who could not be contacted via phone, $\chi^2(2, N = 145) = 2.25, p > .05$

Measures

Screening Measures Completed at the Pediatrician's Office

The Modified Checklist for Autism in Toddlers (M-CHAT). The M-CHAT (Robins et al., 2001)(see Appendix B) is an autism specific questionnaire that contains 23 questions that can be answered yes or no. It has six questions considered to be critical. Critical items (see highlighted items in Appendix B) were determined to best distinguish children with ASD from the remainder of the norming sample, using discriminate function analysis. The M-CHAT was normed for children between the ages of 18 to 30 months. However, to maintain simplicity and to gather data about sensitivity and specificity across the age range of study participants, it was used on the entire sample in the Each Child study. For the purposes
of this study, a positive initial screen for autism symptomatology coincided with an M-CHAT initial score of 3 or more total failed responses or 2 or more failed critical responses. The M-CHAT has sensitivity rates of .85 and specificity of .93 for ASDs (Dumont-Mathieu & Fein, 2005). This indicates that it can be expected to correctly identify 85% of children with an ASD and can be expected to correctly identify 93% of those who do not have an ASD. The M-CHAT follow-up interview is designed to

indicate risk for ASD by clarifying the responses that the parent gave on the parent questionnaire form. Administration consists of following a flowchart of questions aimed at gaining additional information about each response. This interview has been shown to reduce the number of false positives produced by the parent questionnaire (Robins et al., 2001). Although the M-CHAT is copyrighted, the authors offered free use of the instrument via the internet.

The Communication and Symbolic Behavior Scales Developmental Profile-Infant Toddler Checklist (ITC). The ITC (Wetherby & Prizant, 2002) (see Appendix C) is a parent report questionnaire intended for children between the ages of 6 and 24 months of age. It is comprised of 24 questions related to the frequency of specific behaviors in the following domains: social skills, speech, and communication skills. While the ITC is not an ASD- specific screener, the developmental domains of the ITC are considered important in the identification of ASD. Response options on the ITC include: "Not Yet," "Sometimes," or "Often"; however, for some items, parents are asked to respond by quantifying behaviors such as number of words spoken, number of blocks stacked, etc.

A positive screen on the ITC is indicated by scores below a specified cutoff score for the child's age range. Cutoff scores according to age are based on scores that are at, or below, the 10^{th} percentile for the standardized norms (Wetherby & Prizant, 2002). In a study investigating the effectiveness of the ITC for screening and evaluation of children with ASD it was found to correctly identify 88.9% of children who were positive for ASD and 94% of those who were negative (Wetherby et al., 2004). Internal consistency for the ITC is .95 indicating that scores for ITC items correlated with each other at a high level and, thus, are likely to measure the same general construct. Interrater reliability for

the ITC is high in a range between .90 and .97. Mean scores in the standardization sample (*n*=2188) show a pattern of score increases consistent with developmental progression. The ITC also has a strong predictive validity (correlations of .80 for 12-17 months of age and .88 for 18-24 months) with the in-depth caregiver questionnaire that is part of the Communication and Social Behavior Scales measurement system. When cutoff scores on these measures were exceeded, the questionnaires were readministered during a phone interview to clarify responses and to obtain parent concerns.

Telephone Interview

Parent Concerns Questionnaire (PCQ). The PCQ is designed to record parental concerns about children's development. The scale consists of one open-ended question, that is, "Do you have any concerns about your child's development or behavior?" Responses to this question are coded according to eight categories: no concerns, speech/language/communication concerns, social behavior concerns, stereotyped behavior concerns, motor delay concerns, medical concerns, behavior/temperament concerns, and general developmental concerns. Instructions for the measure required that researchers query parents about a particular concern until a code could be assigned. During a pilot study using this questionnaire, Ozonoff et al. (unpublished) trained coders to acceptable levels of reliability. All kappa values were above .70, indicating high levels of interrater agreement.

For the purpose of this study, in-person screening instruments (ADOS-T, Mullen, Vineland) were used to detect symptoms reflecting the following PCQ symptom categories: speech-language concerns, social behavior concerns, stereotyped behavior

concerns, and motor delay concerns. There were spaces on the Clinical Judgment form where the presence or absence of symptoms within each of these categories could be recorded. This allowed symptoms presented by the child during screening to be directly compared to the concerns reported by the parent on the PCQ. A description of each PCQ category and the instruments used to detect symptoms within them are provided in Table 3.

Finally, parents were asked some additional questions (see Appendix B) based on The American Academy of Pediatrics algorithm risk factors. These questions also asked about the presence of siblings with ASDs and about other individuals with concerns regarding the child's development.

In-person Screening Measures

The Autism Diagnostic Observation Schedule (ADOS). The ADOS (Lord et al., 1999) was given to identify autistic symptomology and to support clinical judgment. In preliminary studies with a nonverbal population between ages 12 and 30 months, the ADOS-T was shown to correctly identify 95% of individuals with ASDs and 95% of individuals without ASD. In a population of verbal children of the same age, it was shown to correctly identify 93% of individuals with ASD and 95% without ASD (Luyster et al., 2008).

The Infant-Toddler Social and Emotional Assessment - Parent Form (ITSEA PF). The ITSEA PF (Carter & Briggs-Gowan, 2005) was also administered to support clinical judgment. This measure is designed to obtain parent report data about the child's

Table 3

Description of PCQ Symptom Categories and Instruments Used to Detect Symptoms within Each

PCQ Category	Description	Instruments used to detect symptoms
Speech-language	Refers to the production of speech, babbling, and language comprehension.	ADOS, Mullen, CSBS-ITC
Social behavior	Refers to social engagement, reciprocity, and attention as well as eye contact, response to name, following gaze or points of others, shyness/social hesitancy, imitation, and social, functional, or symbolic play.	ADOS
Stereotyped behavior	Refers to rigid, repetitive, or otherwise odd behavior in the sensory, motor (odd hand/arm/body posturing), or object-use domains as well as excessive mouthing.	ADOS
Motor delay	Refers to delays in achieving motor milestones and/or general clumsiness.	ADOS, Mullen

development and to analyze emerging social-emotional development in order to identify developmental delays. The ITSEA PF includes 166 items, grouped according to 17 subscales that address four broad domains. It was normed on a national sample of 600 children ages 12 to 36 months. Clinical groups for the test included those with language delays, premature children, and children with other diagnosed disorders.

Mullen Scales of Early Learning. The Mullen (Mullen, 1995) is a standardized, normed measure that is used to assess language, motor, and perceptual abilities in children aged birth to 6 months. The Mullen includes five scales that measure development in the areas of gross motor, visual reception, fine motor, expressive language, and receptive language. Test-retest reliability coefficients exceed .70, indicating a high degree of stability over time. Interrater reliability coefficients exceed .90. Internal-consistency reliability for the Mullen has median values ranging from .75 to .83, with the internal reliability of the composite Mullen score having a median value of .91. Concurrent validity shows the Mullen to have higher correlations with other cognitive measures (.53-.59) than psychomotor measures (.21 to .52). The Mullen Early Learning Composite score correlates .70 with other mental development measures and .43 with psychomotor development measures, indicating its validity as a measure of global cognitive ability. The Mullen has correlations ranging from .65 to .82 with other measures of language ability in the relevant age range (Mullen, 1995).

Vineland Adaptive Behavior Scales, Second Edition, Survey Interview Form (Vineland II). The Vineland II (Sparrow, Cicchetti, & Balla, 2005) is an adaptive measure used to ascertain the child's level of age-appropriate functioning in the domains of Communication (receptive and expressive, written domain not applicable) Daily

Living Skills (personal, domestic, community), Socialization (interpersonal relationships, play and leisure time, and coping skills), and Motor Skills (gross and fine). An optional Maladaptive Behavior Index was not used. The Vineland II also yields an overall adaptive behavior composite score. The interview was conducted in Spanish when appropriate.

For ages birth to 5, internal-consistency reliability for the Vineland II is between .80 and .85. For the Adaptive Behavior Composite, in children aged birth through 6, it is .87. Interinterviewer reliability across domains is from .48 to .75. Test-retest reliability for the Adaptive Behavior Composite is .96 for ages birth to 2 and across domains it ranges from .75 to .96 (Sparrow, Cicchetti, & Balla, 2005). The validity of the Vineland II for use in an ASD population was determined outside the age range of the sample used for this study; however, it showed significant differences from the non-ASD sample (Sparrow et al., 2005).

Brief medical history questionnaire. Parents invited for an in-person screening were asked to answer a brief set of questions about their child's health and medical history (see Appendix E). These results were used to determine maternal age and to support clinical judgment. A Spanish version was used when appropriate.

RESULTS

Research Question 1

Are there critical concerns reported on the Parent Concerns Questionnaire (PCQ) that predict whether the child is determined to have ASD or not? Categories of concern on the PCQ were rank ordered according to how frequently they were reported by parents of children that (1) screened negative for ASD symptoms after the phone interview, (2) screened positive for ASD symptoms after the phone interview and were consequently invited for in-person screening, (3) were invited but declined or did not show up for in-person screening, (4) screened negative after in-person screening, (5) screened negative for ASD but positive for speech delay after in-person screening, and (6) were suspected of ASD after in-person screening.

For each of these groups, the percentage of parents who reported concern in each symptom category was calculated (see Table 4 and Figure 2). This was accomplished by dividing the number of parents reporting concern in the symptom category by the total number of parents in the outcome group.

Speech-language was the most common concern reported by parents whose children screened negative for ASD after the phone interview. It was reported by 22 (18.5%) of the 119 parents in this group. Of these parents, 5 (4.2%) reported concern about motor delay, 1 (0.8%) reported concern about stereotyped behavior, and none

Table 4

Number and Percentage of Parents Who Expressed Concern in Each Symptom Category

Screening Results	Language	Social behavior	Stereotyped Behavior	Motor Delay	More than One Category
Negative After Phone Interview (*n*=119)	22 (18.5)	0	1 (0.8)	5 (4.2)	2 (1.6)
Positive after Phone Interview (*n*=41)	23 (56)	3 (7)	4 (10)	6 (15)	6 (15)
Negative after In-person (positive for speech delay) (*n*=15)	10 (16)	1 (7)	1 (7)	2 (13)	2(13)
Negative after In Person (negative for speech delay) (*n*=1)	0	0	0	0	0
No-Show/Declined In-Person (*n*=15)	6 (40)	1 (6.6)	1 (6.6)	1 (6.6)	0
Positive after In-Person (*n*=10)	7 (70)	2 (20)	2(20)	2 (20)	5 (50)

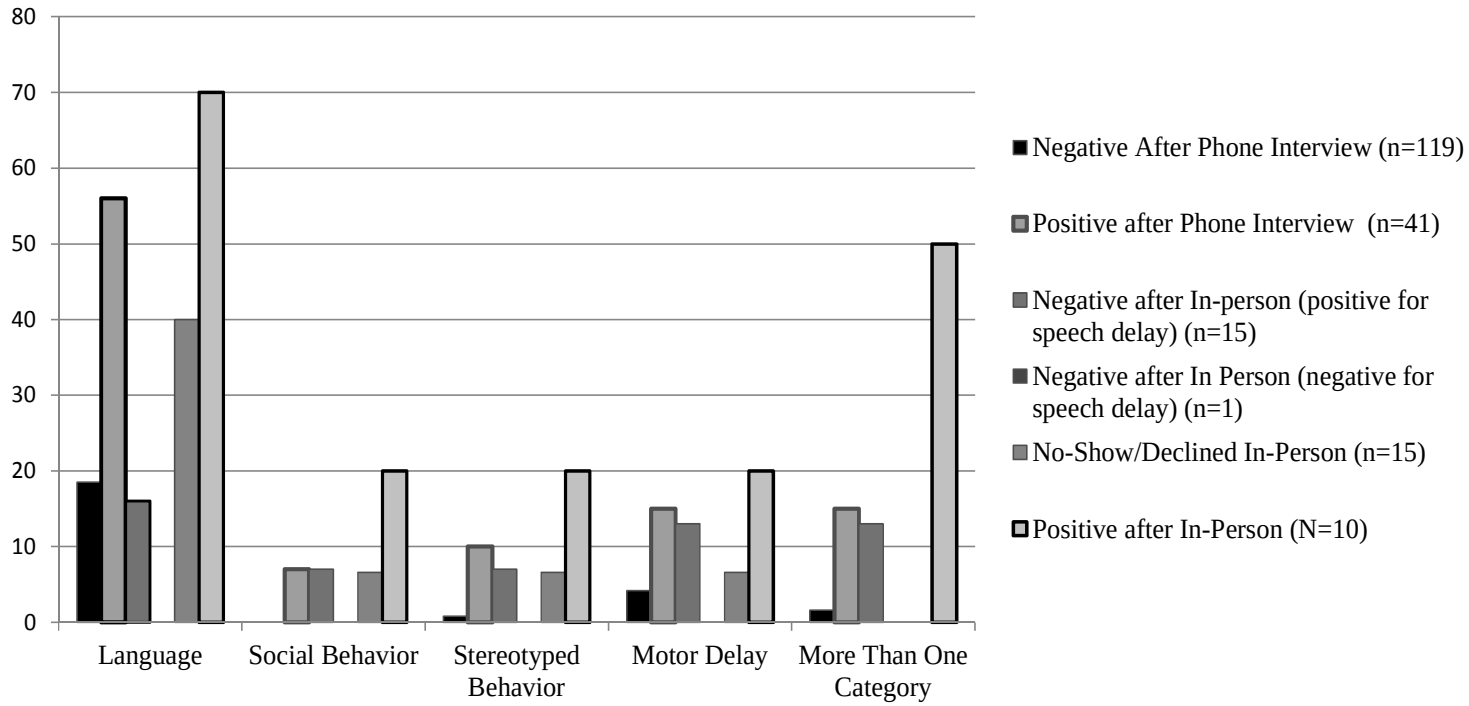

Figure 2. Percentages of parents from six groups who reported concerns in each category.

reported concern about social behavior. Two (1.6%) of these parents had concerns in more than one symptom category.

The group of parents whose children screened negative for ASD after the phone interview included 11 parents whose children screened positive for speech-language delay in the absence of ASD. Six (55%) of these 11 parents reported concerns about speech-language. No other concerns were reported by these parents.

Parents whose children screened positive for ASD symptoms after the phone interview were also concerned about speech-language more often than other ASD symptoms. Of the 41 parents, 23 (56%) had expressed concern about speech-language, 6 (15%) had expressed concern about motor delay, 4 (10%) had expressed concerns about stereotyped behavior, and 3 (7%) had expressed concern about social behavior. Six (15%) had concerns in more than one category.

Of the positive phone screens, 15 parents declined or did not show up for in-person screening; these parents had reported concerns about speech-language delay more often than other ASD symptom; 6 (40%) of these parents reported concerns about speech- language delay, 1 reported concerns about stereotyped behavior, 1 reported concerns about motor delay, 1 reported concerns about social behavior, and none reported concerns in more than one category.

Of those who did show up for in-person screening (*n*=26), speech-language was also the most frequent concern reported. Seventeen (65%) of these parents reported concerns about speech-language, 5 (19%) reported concerns about motor delay, 3 (12%) reported concerns about social behavior, 3 (12%) reported concerns about stereotyped behavior, and 6 (23%) reported concerns in more than one symptom category.

Sixteen parents had children who screened negative for ASD after the in-person screening. This included 15 parents with children who screened positive for language delay in the absence of ASD at this point and 1 parent whose child screened negative for all ASD symptoms at this point. The parent of the 1child who was judged to have no ASD symptoms had not reported any concerns on the PCQ. Of the 15 parents whose children screened negative for ASD but positive for speech delay, 10 (62%) reported speech-language concerns, 2 (13) reported motor delay concerns, 1 (7%) reported social behavior concerns, and 1 (7%) reported stereotyped behavior concerns. Two (13%) of these parents had reported concerns in more than one symptom category.

Speech-language concern was again the most frequently reported concern in the group of parents whose children screened positive for ASD after in-person screening. Of these 10 parents, 7 (70%) had reported being concerned about speech language, 2 of these parents (20%) had reported being concerned about social behavior, 2 (20%) had reported being concerned about stereotyped behavior, 2 (20%) had reported being concerned about motor delay, and 5 (50%) had concerns in more than one symptom category.

Research Question 2

If the parent sought assistance to address concerns about their child's development, which concerns reported on the Parent Concerns Questionnaire caused them to seek assistance? Of the 10 parents whose child was suspected of ASD after in-person screening, 6 reported having sought assistance to address concerns about their child’s development. Speech-language was the concern reported most often by these

6 parents. Four of them reported speech-language concerns, 2 reported concerns regarding social behavior, 2 reported concerns about stereotyped behavior, and 1 reported motor delay concerns. Three of these parents had reported concerns in more than one symptom category. However, no pattern of concerns was found to be present that might have predicted whether or not parents of children who were suspected of ASD after in-person screening reported having sought assistance (see Figure 3).

	Language		**Social Behavior**		**Stereotyped Behavior**		**Motor Delay**		
	Clinical Judgment-Symptoms Present	Parent Reported Concern	Clinical Judgment-Symptoms Present	Parent Reported Concern	Clinical Judgment-Symptoms Present	Parent Reported Concern	Clinical Judgment-Symptoms Present	Parent Reported Concern	**Parent Reported Having Sought Assistance**
1	X	X	X		X		X		
2		X	X		X		X	X	
3	X		X		X		X	X	
4	X	X	X		X				
5		X	X		X	X			X
6	X	X	X		X				X
7	X		X				X	X	X
8	X	X	X	X	X	X	X		X
9	X	X	X	X	X				X
10	X		X		X		X		X

Figure 3. Clinical judgment and parental concerns regarding the presence of symptoms for the group of parents who sought assistance and whose children screened positive for ASD.

Research Question 3

Which ASD symptoms determined to be present during screening are most likely to have been reported by the parent on The Parent Concerns Questionnaire? To answer this question, the percentage of accurate parental concerns was calculated for each symptom category. A concern was considered accurate if symptoms within a category were reported by the parent and symptoms within that same category were judged to be present by a qualified clinician during in-person screening. Percentages of accurate parental concerns were calculated for each symptom category as follows: (1) the data file was filtered so that it only contained those cases in which the symptom was judged to be present during in-person screening; (2) the number of these cases in which the parent reported concern for the symptom on the PCQ was determined; and (3) a percentage was calculated by taking the number from step 2 (determined by the PCQ) and dividing it by the total number of positive cases (determined in step 1) (see Table 5 and Figure 4).

Speech- language delay was found to be the most frequent presenting symptom for which parents had accurately reported concern. Of the 24 parents whose children displayed speech and language delays during the in-person screening, 16 (67%) had reported being concerned about speech-language on the Parent Concerns Questionnaire; 8 (33%) of these parents had reported that they had no concerns in this area. Of parents whose children displayed abnormal social behavior during the in-person screening, 2 (18%) had reported being concerned on the PCQ; 9 (82%) had reported no concerns in this area. Similarly, of parents whose children demonstrated stereotyped or restricted behaviors or interests, 2 (22%) had reported being concerned while 7 (78%) had reported no concerns. Motor delay was reported to be a concern by 4 (57%) parents whose

Table 5

Number and Percentage of Parents Concerned About Different ASD Symptoms

Symptoms Judged to be present during in-person screen	Parents Concerned (%)
Speech/ Language Delay (*n*=24)	16 (67)
Social behavior (*n*=11)	2 (18)
Stereotyped/ Restricted Behavior (*n*=9)	2 (22)
Motor Delay (*n*=7)	4 (57)

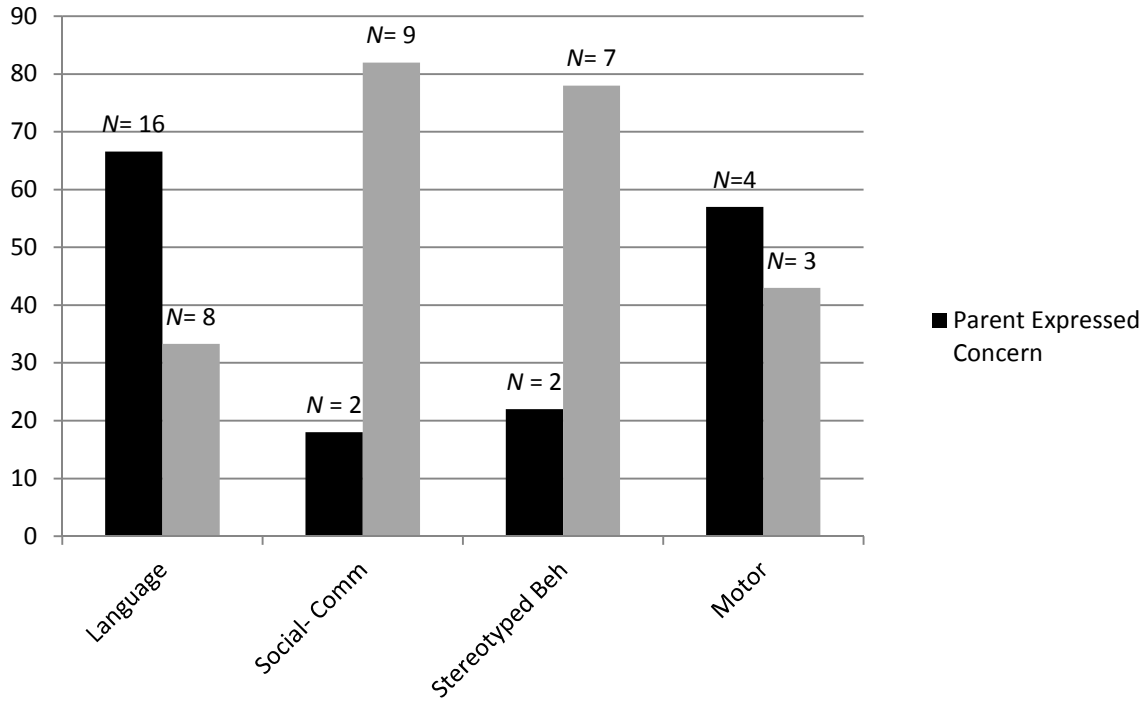

Figure 4. Percentage of parents who accurately expressed concern in each category.

children were judged to display these symptoms during in-person screening and 3 (43%) of these parents missed motor delays that were judged to be present.

Supplemental Research Question 1

Does having one or two parents in the home predict whether parents accurately report symptoms of ASD? Because the sample included only two single-parent households, the effect of one versus two parents in the home could not accurately assessed.

Supplemental Research Question 2

Does having older children predict whether parents accurately report symptoms of ASD? To answer this question, percentages of parents who were in agreement with clinical judgment (made during in-person screen) about the presence *or* absence of symptoms within each category were calculated for the two groups (with older siblings vs. without older siblings)(see Table 6 and Figures 5-6). This situation was termed an "agreement." The percentages of parents in each group who had reported no concerns in a category where clinical judgment determined that the child presented symptoms (these were termed "misses") were also calculated for each symptom category.

Of parents for whom the child in question was their first born (no older siblings), 67 % agreed with clinical judgment regarding the presence or absence of abnormal social behavior and 33 % missed these symptoms; when the child had an older sibling, 57 % of parents agreed with clinical judgment and 36% missed abnormal social behavior. For

Table 6

Percentage of Parents With and Without Older Children Who Reported Concern in Agreement With Clinical Judgment

	Agreement with Clinical Judgment about Social Behavior	Agreement with Clinical Judgment about Stereotyped Behavior	Agreement with Clinical Judgment about Speech-Language
First Child (*N*=12)	8 (67%)	10 (83%)	9 (75%)
Older Sibs (*N*=14)	8 (57%)	9 (64%)	9 (64%)

	Speech-Language			Social Behavior			Stereotyped Behavior			Motor			
	Language Delay Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Motor Delay Symptoms Present	Recognized By	Symptoms Missed By Parent	Screening Results
Older Sibling	X	C	M										Speech/Cognitive
	X	C	M										Speech
	X	P/C											Speech
	X	C	M	X	C	M				X	P/C		ASD
	X	C	M										Speech/Cognitive
													No Concern
	X	P/C											Speech/Cognitive
	X	P/C											Speech
	X	P/C		X	C	M	X	C	M				ASD
	X	C	M	X	C	M	X	C	M	X	P/C		ASD
	X	P/C			P			P			P		Speech
	X	P/C											Speech
	X	P/C		X	C	M	X	C	M				ASD
	X	P/C		X	C	M	X	C	M	X	P/C		ASD

Figure 5. For children with older siblings: symptoms determined to present during in-person screening (X), symptoms recognized by parent (P) and/or clinician (C) at in-person screening, and symptoms missed by parent (M).

	Speech-Language			Social Behavior			Stereotyped Behavior			Motor			
	Language Delay Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Screening Results
First Born Child	X	C	M	X	C	M	X	C	M	X	C	M	ASD
				X	P/C		X	P/C		X	P/C		ASD
													No Concern
		P		X	C	M	X	P/C					ASD
													No Concern
	X	P/C								X	P/C		Speech/Cognitive
	X	P/C		X	C	M							Speech
	X	P/C		X	C	M	X	C	M	X	C	M	ASD
	X	C	M										Speech
	X	P/C											Speech
	X	P/C		X	P/C		X	P/C		X	C	M	ASD
	X	C	M										Speech
	X	P/C											Speech

Figure 6. For first-born children: symptoms determined to present during in-person screening (X), symptoms recognized by parent (P) and/or clinician (C) at in-person screening, and symptoms missed by parent (M).

first born children, 83 % of parents were in agreement with clinical judgment about stereotyped behavior symptoms and 17 % missed symptoms in this category; for children with older siblings, 64 % of parents expressed concerns in agreement with clinical judgment and 29% missed symptoms. Pertaining to speech-language delay, 75 % of parents reporting concerns for first born children agreed with clinical judgment and 25 % missed symptoms; 64 % of parents reporting concerns for children with older siblings agreed with clinical judgment and 36 % missed speech-language symptoms.

Analysis using a chi square test indicated that parents of first born children and those with older siblings did not differ significantly ($P \leq .05$) in their agreement with clinical judgment about the presence of social behavior $X^2(1, N = 25) = 0.07$, $p = 0.7895$, stereotyped behavior $X^2(1, N = 25) = 0.68$, $p = 0.4095$, or speech language symptoms $X^2(1, N = 26) = 0.35$, $p = 0.5551$.

Supplemental Research Question 3

Does the age of the mother predict whether parents accurately report symptoms of ASD? Maternal ages were obtained from the medical history form filled out during in-person screening (see Appendix E). For the analysis of this question, only concerns reported by mothers were considered. Mothers were broken up into three age groups. These age groups were thought to represent relatively distinct periods in the woman's life that may affect her recognition of abnormalities in a child's development. The 3 age groups were (1) mothers who had the child when they were 23 years of age or younger, (2) mothers who had the child when they were between 24 and 32 years of age, and (3) mothers who had the child when they were between 33 and 38 years of age. Percentages

of parents with concerns in agreement with clinical judgment as to the presence or absence of symptoms within each category were calculated (see Table 7 and Figure 7). Percentages were also calculated for those in each group who missed concerns that were judged to be present at in-person screening. Additionally, percentages of parents within each age group who had sought assistance for their concerns were calculated (see Table 8).

All mothers 23 and under (*N*=4) were in agreement with clinical judgment about the presence (or absence) of social behavior symptoms as well as stereotyped behavior. Regarding speech-language concerns, 75 % of these parents were in agreement with clinical judgment while 25 % missed symptoms in this category. One mother (25%) in this age group sought assistance for her concerns.

Of mothers aged 24 to 32 (*N*=14), 57 % agreed with clinical judgment regarding the presence of abnormal social behavior and 36 % missed symptoms in this category, 64 percent agreed about stereotyped behavior and 29 % missed symptoms in this category, and 93 % agreed about speech-language delay while 7 % missed these symptoms. Six (43%) of the mothers in this age group sought assistance to address their concerns.

Table 7

Percentage of Mothers in Different Age Groups Who Reported Concern in Agreement With Clinical Judgment

	Agreement with Clinical Judgment about Social Behavior	Agreement with Clinical Judgment about Stereotyped Behavior	Agreement with Clinical Judgment about Speech-Language
Parent 23 and under (*N*=4)	4 (100%)	4 (100%)	3 (75%)
Parent 24-32 (*N*=14)	8 (57%)	9 (64.2%)	13 (92.8%)
Parent 33-38 (*N*=4)	3 (75%)	3 (75%)	2(50%)

Groups By Maternal Age	Maternal Age at child's birth	Speech-Language			Social- Comm			Stereotyped Behavior			Motor			Screening Results
		Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed By Parent	Symptoms Present	Recognized By	Symptoms Missed Motor	
33 & Over	38													No Concern
	37	X	P/C											Speech/Cognitiv
	34	X	C	M	X	C	M	X	C	M	X	C	M	ASD
	33	X	C	M										Speech
24-32	32	X	P/C			P			P			P		Speech
	30	X	P/C											Speech
	28	X	P/C		X	P/C		X	C	M				ASD
	27													No Concern
	27		P		X	C	M	X	P/					ASD
	27	X	P/C											Speech
	26													No Concern
	26	X	P/C		X	C	M	X	C	M				ASD
	26	X	P/C		X	C	M	X	C	M	X	P/C		ASD
	26	X	P/C								X	P/C		Speech/Cognitiv
	26	X	P/C		X	C	M							Speech
	24	X	P/C		X	C	M	X	C	M	X	C	M	ASD
	24	X	C	M										Speech
	24	X	P/C											Speech
23 & Under	23	X	P/C											Speech
	22	X	P/C		X	P/C		X	P/		X	C	M	ASD
	22	X	C	M										Speech
	17	X	P/C											Speech

Figure 7. For mothers in three age groups: Symptoms determined to present during level 2 screening (X), symptoms recognized by parent (P) and/or clinician at level 2 screening (C), and symptoms missed by parent (M).

Table 8
Percentage of Mothers within Each Age Group Who Sought Assistance for Their Concerns

Parent Age	Assistance Sought	No Assistance Sought
Parent 23 and under (*N*=4)	1 (25%)	3 (75%)
Parent 24-32 (*N*=14)	6 (43%)	8 (57%)
Parent 33-38 (*N*=4)	2 (50%)	2 (50%)

In the oldest group (aged 33-38, *n*=4), 75 % of mothers agreed with clinical judgment in their concerns about both social behavior symptoms and stereotyped behavior. Of these mothers, 25 % missed symptoms in the social behavior category and 25 % missed symptoms in the stereotyped behavior category. In the speech language concern category, 50 % of parents had concerns that agreed with clinical judgment while 50 % missed symptoms in this category. Two (50%) of these mothers sought assistance for their concerns.

A chi-square test was performed to examine the relationship between maternal age and the accuracy of the concerns reported. Results indicated that the accuracy of concerns reported, that is, agreement with clinical judgment, did not differ significantly ($P \leq .05$) between age groups X^2yates (2, N = 22) = 1.615078, p = 0.446. Another chi-square was performed in order to examine the relationship between maternal age and whether or not assistance was sought to address concerns. Again, this test failed to detect significant differences between age groups X^2yates (2, N = 22) =0.053769, p = 0.973.

DISCUSSION

The goal of this study was to investigate parents' concerns regarding the symptoms of ASD in order to determine which symptoms parents are most likely to miss and what factors are related to a parent becoming concerned and their seeking assistance to address concerns. This study utilized the Parent Concerns Questionnaire to obtain parents' concerns about the symptoms of ASD just before symptoms were formally assessed.

ASD Symptoms Reported and Missed?

The first research question examined in this study sought to evaluate which ASD symptoms determined to be present during screening were most likely to have been reported by the parent. Results suggest that parents were most likely to miss abnormal social behavior (e.g., eye contact, imitation, use of gestures) and unusual stereotyped or repetitive behaviors (e.g., arm flapping, odd use of toys). They were least likely to miss language delay.

These findings suggest that parents recognize and become concerned about language delay more readily than other ASD symptoms that their child presents with. Perhaps this is because parents have a better understanding of the typical developmental course for language acquisition. Another possible explanation is that concerns about

language are easier to conceptualize and put into words for an individual who does not have the terminology needed to describe autistic behavior (i.e., stereotyped behavior or unusual social interaction). When these behaviors are present, a parent may be hesitant to report that they are concerned because they cannot describe what they are concerned about (e.g., "He just acts a little strangely"). Perhaps parents fail to become concerned about their child's atypical social interaction because they have become accustomed to it or because they have explained it away. Previous research has demonstrated that, over time, a parent may become increasingly tolerant of social and emotional withdrawal in their child without recognizing it as a problem (Maestro et al., 1999). Parents' failure to recognize social behavior symptoms and stereotyped-repetitive behaviors has implications for the identification of ASDs because abnormalities in these areas appear to be the first detectable indicators of ASD (Adrien et al., 1993; Baranek, 1999; Siegal et al., 1988; Stone et al., 1999).

Which Symptoms Are Predictive of ASD?

The second research question proposed by this study was the following: Are there critical concerns reported on the Parent Concerns Questionnaire that predict whether the child is determined to have ASD or not? The data did not clearly indicate categories of parental concern predictive of ASD. Data did, however, suggest that there may be a predictive pattern of concern.

Consistent with previous research (De Giacomo & Fombonne, 1998; Wetherby et al. 2004; Young et al., 2003), speech language concern was reported more frequently by parents of ASD positive children than by other parents. Concern in the speech language

category cannot, however, be interpreted as predictive of ASD because parents of ASD positive children reported concerns in all categories more frequently than the other parents. Looking at concerns across categories, the data suggests that parents of ASD positive children are more likely than other parents to be concerned about more than one ASD symptom. This finding reflects previous research (Wetherby & Prizant, 2002) as does the finding that parents of typically developing children most often express concern about language delay only (Glascoe, 1997).

What Symptoms Are Reported by Parents Who Seek Assistance?

The third research question explored by this study was as follows: If the parent sought assistance to address concerns about their child's development, which concerns did they report on the PCQ? Concerns about language delay were the most commonly reported concerns of parents who had sought assistance. Other concerns were reported much less frequently by these parents. The subgroup of parents who sought assistance and whose children screened positive for ASD also reported concerns about language delay most frequently. However, language delay was the most common concern reported by all parents (whether or not they sought assistance), making it difficult to draw conclusions about those who sought assistance based on this concern.

To further address this question, parents who expressed concern in each symptom category were analyzed to determine what percentage of them had sought assistance. Results of this analysis suggest that parents who reported concern about social behavior were the most likely to have sought assistance. Taken together with the finding from research question two (that parents were less likely to become concerned by

social abnormalities than by language delay), this finding suggests that when parents do become concerned by these symptoms, they are more likely to do something about their concerns than when they become concerned about other symptoms such as language delay. This may be an indication that current efforts to educate parents about the early symptoms of autism are motivating parents to take action in reaction to specific social and behavioral abnormalities common to ASDs.

What Factors May Influence Parental Report of ASD Symptoms?

Other factors that may have impacted parental report of ASD symptoms were also explored. Results indicated that the presence of older siblings did not significantly influence whether or not parents reported symptoms that were in agreement with clinical judgment.

The effect of maternal age on the accuracy of parental concerns and assistance sought to address these concerns was also considered. Results suggest that maternal age does not significantly impact a parent's ability to recognize the symptoms of ASD or the likelihood that they will seek assistance to address these concerns. However, it was difficult to conclusively determine the impact of maternal age because the sample size for which this data was collected was small and because a majority of the mothers were around the same age (in their mid-20s).

Another factor considered in this study was whether having one or two parents in the home predicted how often parents accurately report symptoms of ASD. However, because the sample included only two single-parent households, the contribution of this factor could not be accurately assessed.

Limitations

There are a number of study limitations, sample size being one. In an attempt to obtain parental concerns before a diagnoses of ASD was made, 813 children were screened. However, as would be expected given the prevalence rate, only a small percentage screened positive for ASD. A total of 10 children were suspected of ASD after screening. With this small number of cases, it is difficult to make observations that would be expected to generalize to the true population of children with ASD. To compensate for this limitation, all ASD symptoms that were judged by a clinician to be present were included in the analysis regardless of the child's screening outcome. This allowed for some relevant conclusions to be drawn from the data. However, in the exploration of some research questions, the number of cases displaying the symptom in question was too small to suggest that findings might generalize. A related limitation within this study is the restricted range of families or children possessing the qualities or factors in question. For example, as was mentioned above, the effect of a one- versus a two-parent household on the accuracy of parental concern could not be evaluated because there were only two single parent families in the sample. Similarly, the effect of maternal age could not be explored because the range of ages was not sufficiently large.

Another limitation of the study was the method used to collect data, including the interviewing of parents. Data on parental concerns were collected during a phone interview. Parents may have answered questions differently on the phone than they would have in person due to the less personal nature of a phone call or because they may have desired to get off the phone quickly. Also, the open-ended question format of the PCQ was both a benefit and a limitation. A limitation of this format is that it relies on the

parent's spontaneous recall of concerns across all categories. Queries about concerns within specific categories were not made unless the parent expressed some concern after the initial open-ended question ("Do you have any concerns about your child's development?") and their response could not be coded into a category without querying. It is possible that querying within specific categories would have allowed parents to recount more concerns. On the other hand, it is likely that significant concerns would have been in the forefront of the parent's mind and would have been reported in response to the open-ended question without additional probing.

Future Research

In future research, an attempt to gain a larger sample size of children screening positive for ASD should be made. Also, a sample that included a wider range of family types (e.g., one and two parent) and maternal ages would allow the effect of these factors on parental concerns to be investigated more thoroughly. A larger sample size might also allow for the analysis of concerns reported by parents who have an older child already diagnosed with an ASD. This would allow future research to study the effect of having an older child with ASD on the accuracy of parental concern regarding ASD symptoms in a younger child. Future research should also focus on determining the effects of efforts to educate parents about the early symptoms of ASD on parental concerns so that these efforts may be targeted towards symptoms that are failing to trigger concern. Other methods of collecting parent concern could also be explored. This may include the use of more direct questions about concerns in specific symptom categories. Because the current study found that language delay was the most commonly reported concern of all

parents regardless of their child's screening outcome, it may be useful to investigate factors affecting the emergence of specific concerns within the category of language delay.

Conclusions

The investigator sought information from parents of children with ASD about concerns that they might have had prior to their child being screened for ASD. The intent was to determine which symptoms are most likely to be missed by parents, and which concerns are more likely to predict the results obtained from early childhood screenings. Further, the investigator was interested in information that would help determine what factors contribute to the accuracy of parental report and their seeking assistance to address concerns. Parents of children who screened positive for ASD failed to express concern about social behavior and stereotyped behavior symptoms with which their child presented more frequently than other ASD symptoms. Parents accurately reported language delay more frequently than other ASD symptoms. No specific parental concern was found to be predictive of screening outcome but findings suggest that the presence of concerns in more than one category may predict a positive screen for ASD. Parents who reported concerns about abnormal social behavior and stereotyped repetitive behaviors were more likely to have sought assistance for their concerns than parents who had reported concern in other areas. The presence of older siblings and maternal age does not appear to influence a parent's ability to recognize and become concerned by ASD symptoms. However, the effect of the number of parents in the home could not be assessed because of the limited range of the sample. Taken together it appears parents

could benefit from additional information about the early signs of autism specifically normal versus abnormal social interaction and repetitive, stereotyped play behavior.

APPENDIX A

PARENT CONCERNS QUESTIONNAIRE

PARENT CONCERNS QUESTIONNAIRE MANUAL

Instructions*

General Scoring Guidelines

All concerns indicated by parents in response to the question should be coded. Judgments about whether a concern is legitimate, reasonable, or age-appropriate should not be made.

If a concern is phrased suggesting change over time (e.g., "we used to be worried about this, but now we are not" or "we thought she was doing fine, but now we wonder if she is eating enough"), code the **current** situation.

If a parent mentions behaviors of no concern along with behaviors of concern simultaneously ("His language is coming along great. He's in the middle of the terrible two's and is very hard to control"), code only the concerns.

Mentions more than one concern, number them

If a parent equivocates or rationalizes ("his language seems a little slower than his sisters, but I'm not worried about it"), still code as a concern.

If a parent comment cannot clearly be assigned to a category based on what was stated, query further ("tell me more about that") in an attempt to obtain enough information to assign to a category. Use the "Other Concerns" code only for concerns that clearly fall outside the boundaries of all categories ("She prefers to play with trucks and cars" or "He always puts a finger in his ear when we are taking photographs.").

If the parent explicitly mentions autism or draws comparison to the sibling with autism but is not specific ("He acts like my sister's son did at this age and he has autism" or "Personality-wise he's a lot like his older brother" or "I'm just worried it's autism."), query to get specific area(s) or behaviors of concern that are scoreable ("Well, he doesn't look at us, which is one of the things we noticed about his brother").

No concerns – The parent indicates no concerns or highlights positive attributes about the child or the child's development. This code is mutually exclusive with all other codes and therefore can only be used when no concerns about anything are stated for the whole visit (if both concerns and positive behaviors are mentioned simultaneously, code only the concerns).
"No concerns"
"None" or "Nothing"
"I'm interested how *you* think he did, his language is advanced isn't it?"
"She's talking so much, and she articulates better than her older brother."
"Seems like she's doing fine to us."

Speech/language/communication concerns – Refers to concerns related to the production of speech (expressive language, vocabulary, articulation), non-verbal vocalizations (babbling), reciprocity, intentionality or meaningfulness of communication, gestures (pointing, etc.), and language comprehension. Also include concerns about hearing here.
"He makes sounds but he still won't babble. He doesn't go ba-ba, or da-da or anything."
"She still has very few words…"
"He's talking a lot but even I can't understand him most of the time…"
"Should he be waving bye and hi by now?"
"He'll often repeat my words but doesn't get what I'm saying."
"We're going to get her hearing checked – we wonder if she is hearing everything."

Social behavior concerns – Refers to concerns about social engagement, interest in other people, social or emotional reciprocity, and social attention and may include comments relating to eye contact, response to name, following gaze or points of others, shyness/social hesitancy, imitation, and social, functional, or symbolic play.
"He seems oblivious to other kids at the playground…"
"He seems to avoid eye-contact, as if it physically hurts him."
"She's painfully shy, she won't let go of my leg when other kids are around. Then again her father and I are both pretty shy."
"Sometimes he seems to be in his own little world."
Stereotyped behavior concerns: Rigid, repetitive, or otherwise odd behavior in the sensory, motor (odd hand/arm/body posturing), or object-use domains. Excessive mouthing should also be coded here.
"He walks on his tip-toes when he's wearing shoes."
"She always needs to be holding a matchbox car."
"He covers his ears a lot, even when it doesn't seem too loud."

Motor delay concerns: Concern refers to delays in achieving motor milestones and/or general clumsiness.
"My pediatrician told me that a lot of kids don't walk by 12 months but now he's 17 months and still not walking."
"She still falls down a lot, more than it seems like she should."

"He's so cautious about everything. His sister was climbing trees before she could walk whereas he won't even climb down off our bed."

Medical concerns: Concern refers to a specific medical issue/condition or general health problems. Include problems with feeding, sleeping, and elimination here.

"She has had acid-reflux ever since she was a little baby and it's been difficult to treat."
"He seems to get sick more than most kids."
"She gets a rash around her mouth when she eats fruit"
"He seems small for his age, doesn't he?"
"She's constipated a lot, especially since she's started eating real food."
"He still isn't sleeping through the night."
"She only eats a few bites, then stops."

Behavior/temperament concerns: Any concerns related to behavior or temperament are coded here. This includes activity level (constant movement, passive); attention (inability to settle down, distractibility); behavioral regulation (intensity of response, aggression, impulsivity); adaptability (compliance, difficulty with change, transitions, ability to soothe); mood/general disposition (happy, cranky, anxious; poorly modulated affect).

"She won't sit still for even a minute. I can't get her to listen to a story."
"He can be so stubborn."
"They've officially warned us at school that if he bites again he's out."
"He won't let me put him down when we go somewhere new"
"Doesn't comfort self."
"He gets angry and slaps. He has a real temper."

General developmental concerns: Concerns about development that are general. Also code cognitive and adaptive/daily living concerns here.

"He's just hitting his milestones later than my other kids."
"She seems to be off-track developmentally."
"He is physically behind, maybe because he was premature."
"Does he seem delayed to you?"
"She's not holding her own bottle yet."
"He doesn't know his colors. Is that normal?"

Other Concerns: Use this category for concerns that do not fit into any other category and, even after querying, cannot be assigned to another specific code.

"In recent photos, he always has his finger in his ear."
"I wonder if some of my health issues could have affected my kids."
"She prefers to play with trucks and cars."

Subject ID _____ Date _____

Visit Age _____ Respondent _____

Parent Concerns Questionnaire

"Do you have any current concerns about [child's] development or behavior?"

Check all that apply and record comments as close to verbatim as possible in the space provided.

- ❑ **No concerns**

- ❑ **Speech-language concerns**

- ❑ **Social behavior concerns**

- ❑ **Stereotyped behavior concerns**

❑ **Motor delay concerns**

❑ **Medical concerns**

❑ **Behavior/temperament concerns**

❑ **General developmental concerns**

❑ **Other concerns**

If parent mentions more than one concern:

"You've mentioned a few things you're worried about. Which one concerns you most?"

1 = Speech-language
2 = Social behavior
3 = Stereotyped behavior
4 = Motor delay
5 = Medical
6 = Behavior/temperament
7 = General developmental
8 = Other

APPENDIX B

ADDITIONAL QUESTIONS

1) Have you done anything about any of these concerns?

If yes: What have you done? Which concern caused you to (*whatever action they took)* ?

2) Are there two parents in your household?

3) Does XX have older siblings?

If yes: How many?

4) Does XX have younger siblings?

If yes: How many?

5) Have any of these siblings ever been diagnosed with an autism spectrum disorder?

If yes: How many?

6) Has anyone else expressed any concern about XX's development? (eg. friends, relatives, medical professionals)

If yes: were these concerns expressed before *you* had a concern?

APPENDIX C

MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (MCHAT)

M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.? Yes No
2. Does your child take an interest in other children? Yes No
3. Does your child like climbing on things, such as up stairs? Yes No
4. Does your child enjoy playing peek-a-boo/hide and seek? Yes No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? Yes No
6. Does your child ever use his/her index finger to point, to ask for something? Yes No
7. Does your child ever use his/her index finger to point, to indicate interest in something? Yes No
8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing,
fiddling, or dropping them? Yes No
9. Does your child ever bring objects over to you (parent) to show you something? Yes No
10. Does your child look you in the eye for more than a second or two? Yes No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears) Yes No
12. Does your child smile in response to your face or your smile? Yes No
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?) Yes No
14. Does your child respond to his/her name when you call? Yes No
15. If you point at a toy across the room, does your child look at it? Yes No
16. Does your child walk? Yes No
17. Does your child look at things you are looking at? Yes No
18. Does your child make unusual finger movements near his/her face? Yes No
19. Does your child try to attract your attention to his/her own activity? Yes No
20. Have you ever wondered if your child is deaf? Yes No
21. Does your child understand what people say? Yes No
22. Does your child sometimes stare at nothing or wander with no purpose? Yes No
23. Does your child look at your face to check your reaction when faced with something unfamiliar? Yes No

Child's Name _____ Child's Date of Birth_____

Child's Zip Code: _____ Child's sex : M F Today's Date _____
Is this the first time you have completed this questionnaire? Yes No Child's race (optional) _____
How was this questionnaire administered? ___Over the phone, ___In-person interview, ___Parent filled out

APPENDIX D

CLINICAL JUDGMENT FORM

Clinical Judgment Form

To be completed by clinician overseeing the administration of the ADOS-T and Mullen.

Autism suspected: YES _____ NO _____

If no, is a speech delay suspected: YES _____ NO_____

Based on the administration of the ADOS-T and Mullen Fine and Gross Motor scales please indicate the presence of clinical concern in the following domains:

Autism-related domains:
Language ____
Social Communication ____
Stereotyped/Restricted Behavior or Interests ____

Other:
Cognitive delay ____
Gross motor delay____
Fine motor delay____
Visual perception delay____
Behavior/Temperament ____

No concerns in any of the above areas present ____

Notes:

_____

_____

_____

Completed by: _____

APPENDIX E

BRIEF MEDICAL HISTORY FORM

Brief Medical History Parent Questionnaire

Child's Name _____ Date of Birth _____

Date of Interview_____ Filled out by _____

Mother's Occupation _____ Father's Occupation_____

Mother's Education _____ Father's Education _____

With whom does your child live:
_____ biological parents _____ step parent _____ single parent _____ adoptive parents
_____ grandparents _____ foster parents ____ other:_____

Does anyone in your family have a history of:

_____ Visual problems _____ Hearing problems _____ Speech problems
_____ Birth defects _____ Mental/Emotional problems _____ Mental retardation
_____ Learning disabilities _____ Behavioral problems _____ Medical problems
_____ Muscle (motor) problems

If yes to any, please explain: _____

_____

Pregnancy/Delivery History:
How old was the mother at the time of the child's birth? _____

During this pregnancy, did the mother experience any unusual illness, condition or accidents. If so, please describe: _____

_____

Did the mother take any drugs or medicines, including tobacco and alcohol, during this pregnancy? _____ yes _____ no If yes, please describe: _____

_____

Length of pregnancy _____ Length of labor _____

Type of delivery: _____ normal, vaginal _____Caesarean _____ breech

Any complications? _____ yes _____ no If yes, please explain: _____

_____

Any unusual conditions at or immediately after birth? _____ yes _____ no

What was the diagnosis? _____

Was the baby kept in the hospital after the mother was discharged? _____ yes _____ no
If yes, for how long? _____ Why? _____

Birth weight _____ lbs _____ oz

What illnesses, accidents, or operations has your child had? Include hospitalizations and hospital emergency room visits.

Problem	Age
_____	_____
_____	_____
_____	_____
_____	_____

Any medical diagnoses? _____ yes _____ no If yes, please describe _____

_____

Has your child taken any kinds of medication regularly? _____ yes _____ no If yes, please describe _____

_____

Has your child ever had:

_____ seizures _____ vision problems _____ speech problems
_____ allergies _____ hearing problems _____ period of unconsciousness
_____ head injury If yes, please describe degree of problem (frequency/severity):

_____

_____

Describe child's present state of health: _____

_____

APPENDIX F

COVER LETTER FOR PARENTS

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Granger Pediatrics is participating in a study with the University of Utah and the Department of Health.

The purpose of the study is to screen for autism and other developmental issues in very young children.

Please complete the attached questionnaires, EVEN IF YOUR CHILD IS DEVELOPING NORMALLY.

Your provider will not know the results today. You may contact the study directly at any time to have any questions answered. The researchers would also like permission to contact you if they have any questions or concerns about your child's screening results.

You may be asked to complete the questionnaires again in the future, in order to help the researchers study children's development over time.

The EACH CHILD Study can be contacted directly at (801) 587-3774.

APPENDIX G

RELEASE OF PROTECTED HEALTH INFORMATION FORM

AUTHORIZATION FOR THE RELEASE OF PROTECTED HEALTH INFORMATION (PHI)

This authorization form complies with all state and federal regulations and MUST BE COMPLETED IN ITS ENTIRETY to be valid.

PATIENT NAME _____ Date of Birth: _____

THIS IS TO AUTHORIZE THAT MEDICAL INFORMATION REGARDING THE IDENTIFIED PERSON BE RELEASED BETWEEN THE FOLLOWING TWO PARTIES:

From/To: **The EACH CHILD Study** To/From: **Granger Medical Pediatrics**
Address: **650 Komas Drive Suite 206** Address: **3725 West 4100 South**
City/State/Zip: **Salt Lake City, UT 84108** City/State/Zip: **West Valley City, UT 84120**

HIPAA laws prohibit disclosure of other facility records including: hospital records, other clinic records, and medical records sent to us by other physicians on your behalf.

SPECIFIC INFORMATION TO BE RELEASED:

_ _ SCREENING QUESTIONNAIRES
_ _ CONTACT INFORMATION

PURPOSE OF DISCLOSURE: **To allow the EACH CHILD study to contact parents and to allow the EACH CHILD study to share evaluation results with the physician.**

This authorization is valid for 360 days from the date of signing, and may be revoked at any time by sending a written request tot the facility releasing my protected health information. Revocation of this authorization shall not affect releases of information made prior to the revocation.

I UNDERSTAND THAT AUTHORIZING DISCLOSURE OF MY PROTECTED HEALTH INFORMATION IS VOLUNTARY AND THAT I NEED NOT SIGN THIS AUTHORIZATION IN ORDER TO ASSURE MEDICAL TREATMENT. I FURTHER UNDERSTAND THAT THE DISCLOSURE OF THIS INFORMATION CARRIES WITH IT THE POTENTIAL FOR UNAUTHORIZED REDISCLOSURE AND THE INFORMATION MAY NO LONGER BE PROTECTED BY FEDERAL CONFIDENTIALITY RULES.

If patient is under 18 or unable to sign for himself or herself, please have parent, legal guardian, or representative fill out the section below:

PARENT/GUARDIAN/REPRESENTATIVE
SIGNATURE:_____
_____

PRINT NAME:
_____

RELATIONSHIP TO PATIENT:
_____

VERIFIED/SIGNATURE WITNESSED BY :
_____

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